



Nothing About Us Without Us

Women of African and Caribbean Heritage
Community Voices Report
November 2024



LOTHIAN
Maternity Voices
Partnership

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CONTENTS

Executive Summary	7
Introduction	15
Background	16
Pregnancy & Birth in Lothian	
Pregnancy & Birth in Scotland	
<i>‘Nothing About Us Without Us’ (NAUWU)</i>	18
The Initiative	
Partnership and Engagement Model	
Community Workshops	
Voices from Community Engagement	
Your experience is Our Experience	25
What My Mother Said	32
What Matters to Me	35
NHS Health Providers Forum	40
Our Recommendations	45
Conclusion	50
Resources for Pregnant Women & Birthing People	51

**The stories collated in this report are
a mixture of joy, resilience, sadness
and aspiration.**

We strived to present stories as they were told to dignify the full experiences and humanity of the Women of African & Caribbean descent who engaged with us. We acknowledge that you may find some of these testimonies distressing. If you have been negatively impacted by reading this report, please contact KWISA where trained staff can offer help and support.

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Mon & Tuesday from 9:30 am to 5:30 pm

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EXECUTIVE SUMMARY

Women of African and Caribbean Heritage (WACH) aspire and desire for positive and affirming pregnancies and births. Yet there is evidence that they continue to disproportionately suffer worse experiences and poorer outcomes compared to women of other ethnicities.

To address this, we convened "Nothing About Us Without Us" (NAUWU)- a community participatory initiative and innovative collaboration model between KWISA Women of African Heritage and NHS Lothian Maternity Voices Partnership (MVP).

We aimed to:

- 1. Convene the expertise of WACH in leading and engaging with our communities**
- 2. Build relationships between communities of WACH and NHS Lothian**
- 3. Explore co-created solutions that are mutually beneficial and aim to improve the experiences and outcomes for Black women accessing maternity services in Lothian**

The initiative is led by a multidisciplinary group of WACH and their allies. The organisers represent people that pregnant women and people may interact with before, during and after their pregnancy in their roles as maternity health workers, doulas, nutritionists, psychologists, social workers, third-sector organisations, legal advisers and representatives from academic institutions. The organisers collectively have lived and professional expertise and experience of pregnancy and birthing within NHS Lothian and other health systems.

The community events and workshops provided a platform for seldom-heard voices to speak up, enabled respectful dialogue, and led to the initiation of collective problem-solving. The key themes from the workshops are summarised under experiences, expectations and aspirations.

Experiences

Women shared a mix of positive and negative experiences of care.

Positive experiences were associated with feeling listened to and having one's concerns valued. Participants who received care from health workers of similar ethnic and cultural backgrounds also reported positive experiences. Some women who had positive experiences were surprised to hear of the negative experiences of others.

Negative experiences were characterised by not being listened to or having concerns disregarded. Many women voiced concerns about their pain being dismissed, misdiagnosis of conditions on darker skin, poor communication and delays in receiving care. Women shared examples of stereotyping, disrespectful and discriminatory care. All of these were thought to contribute towards adverse outcomes for themselves and their babies.

The overall impact of negative experiences of maternity care in Lothian was distrust of care providers and hospitals, loneliness and hypervigilance.

Expectations

We explored participants' expectations by exploring their reference points for pregnancy and birth.

Women prioritised and valued the knowledge, advice and experiences of a respected older female relative or close friend.

Women acknowledged that occasionally advice from 'mothers' clashed with the routine advice from health providers, resulting in confusion and anxiety. Participants also based their expectations on their previous experiences of being pregnant. If this was positive, they were more likely to expect a good outcome. For some the vicarious negative experiences from other WACH through media coloured their expectation for care in Lothian.

Aspirations

All participants expressed a desire for positive outcomes for their pregnancies and birth. **Participants stated that adverse outcomes and experiences were due to the system not being tailored to their specific needs.**

There was some hesitation around expecting things to improve, due to previous examples of engagement with minoritised groups being perceived as a tokenistic ‘tick box’ exercise.

Some participants expressed sympathy for the NHS, acknowledging that the gaps in the knowledge of care providers and the system were due to limitations around time, resources, lack of workforce diversity as well as more challenging issues of implicit biases, microaggressions, and institutional racism.

To overcome this, they suggested provider training on cultural safety, anti-racism and implicit biases. Additionally, women recommended raising awareness of the detection of conditions disproportionately impacting WACH.

To build trust and address hypervigilance and isolation, they suggested providing continuity of care and or supplementing this with the development of community liaison workers- trained WACH who would act as a go-between community and the hospital system. The existence of the NHS MEHIS¹ system was acknowledged but not felt to be comprehensive enough. Some participants cited the AMMA Birthing Companion² model as a model to aspire for.

Finally, to ensure the entire system and all users could benefit from the feedback of WACH, they suggested implementing visible and accountable systems to provide feedback that could be actioned and shared widely across Scotland.

¹ Minority Health Inclusion Service (MEHIS) is an existing NHS advocacy service for minoritised ethnicity communities <https://services.nhslothian.scot/mehis/>

² AMMA Birth Companions are a Glasgow based charity that provide pregnancy services and birth companionship for underserved pregnant people in Glasgow <https://ammabirthcompanions.org/about/>

The NHS staff engagement session was well received.

The attendees reported that pregnancy and birth disparities for WACH were due to multiple factors including- interpersonal and institutional racism, mistrust between service users and their providers, language barriers, limited resources (time and staff capacity), insufficient provider training on diagnosis of conditions and cultural safety when working with minoritised ethnicity service users.

Attendees shared anecdotal examples of disparities in recognition of jaundice, anaemia, pain and newborn vital sign monitoring (APGAR scores).

Key points raised focused around the need for:

- Increased service provider awareness and education about existence and causes of minoritised ethnicity maternity disparities.
- Exploration and sharing of NHS Lothian specific ethnicity disaggregated data to understand causes, monitor trends and improve outcomes.
- More platforms for further discussions about NAUWU within NHS Lothian women & children's services.
- Prioritising improvement strategies in areas in NHS Lothian with highest density of Black, African and Caribbean women.

Our Recommendations

Based on this extensive gathering and listening exercise the NAUWU steering group have designed recommendations to the NHS Lothian Health Board.

The purpose of these recommendations is to:

- Provide enhanced perinatal care and specific support for WACH.
- Increase consistency of maternity staff knowledge, awareness and competence through specific training.
- Improve service systems to eliminate minority ethnic disparities.

Provide enhanced perinatal care and specific support for WACH

1. Address community gaps in knowledge identified by the NAUWU community engagement sessions by delivering specific antenatal classes tailored to the needs of WACH.
2. Request that Public Health Scotland commission and co-produce pregnancy literacy resources with WACH provided in formats that are accessible to people with diverse language and literacy abilities.
3. Prioritise the creation of Community Hubs in in antenatal locality areas of the Lothians with the highest density of WACH in Lothian.
4. Facilitate self-advocacy and empowerment amongst WACH by sharing positive stories and positive change, working closely with third-sector organisations to promote engagement, advocacy and self-efficacy training.
5. Increase collaboration with third sector organisations that support minoritised ethnicity women and support the development of 'Pregnancy and Beyond' Networks, to link WACH to services and peer networks

Increase consistency of maternity staff knowledge, awareness and competence through specific training.

1. Provide co-created regular training about implicit biases, cultural safety, anti-racism and detection of specific conditions in WACH. This training should be mandatory, embedded and evaluated within existing training to ensure sustainability and accountability.
2. Provide opportunities for training to be delivered by WACH so that providers can interact with minoritised ethnicity communities and organisations outside the health care space.
3. Support care providers in attending appropriate community engagement sessions by third-sector organisations held within the community

Improve service systems to eliminate minority ethnic disparities

1. Build trust with communities of WACH by demonstrating a commitment to tackling disparities at the highest level of Health Board leadership to ensure minoritised ethnicity issues are being valued and not tokenised.
2. Improve the monitoring and evaluation of outcomes for WACH by embedding ethnicity disparity reviews into NHS Lothian data collection, clinical governance, assurance frameworks and improvement processes.
3. Invite an advisory group of WACH and relevant third sector organisations to set targets and co-produce Lothian specific strategy to improve outcomes for WACH
4. Review relevant clinical guidelines, adverse outcomes and complaints by ethnicity and agree targets within the Health Board clinical governance and assurance frameworks to eliminate ethnic minority disparities
5. Provide regular (minimum annual) updates on progress to reduce minority ethnicity disparities with community organisations.
6. Leverage existing relationships with academic institutions and Public Health Scotland to advocate for research and funding of innovations that tackle maternal health disparities

7. Share progress with community organisations on the NHS Lothians Equality and Human Rights Strategy³ to be anti-racist, tackle health inequalities, increase recruitment and career development of minoritised ethnicity staff and celebration of diversity in Lothian.

³ In 2023 NHS Lothian launched an Equality and Human Rights Strategy <https://org.nhslothian.scot/equality-human-rights/>

KWISA and NHS Lothian partnered to host Scotland's 1st United Nations Commission on the Status of Women

In March 2023, KWISA and 116 participants from diverse fields, including NGOs, healthcare, government, academia, and social care, united to champion co-creation with women of African and Caribbean descent at Scotland's first-ever NGO Forum for the United Nations Commission on the Status of Women (CSW).

What is the United Nations Commission on the Status of Women (CSW)?

The CSW is the United Nations' largest annual gathering on gender equality and women's empowerment. Taking place over 2 weeks in March, UN member states and activists work together to make progress on global gender equality. The NGO CSW is a forum for non-governmental organisations like KWISA to participate in this important annual meeting.



THE UNIVERSITY
of EDINBURGH

Usher
Institute



This hybrid event was held in partnership with KWISA, NHS Lothian and the University of Edinburgh.

What was the outcome of this meeting?

The leadership of NHS Lothian Women & Children's Services committed to convening and engaging with the expertise of women of African and Caribbean descent in improving outcomes for minoritised ethnicity women giving birth in Lothian.

1. Recognize community expertise, not just experiences
2. Build trust with patience and humility
3. Address unequal access and engagement
4. Redistribute power for true co-creation

*Disrupting the Status Quo of Co-Creation
with
Women of African Descent*



INTRODUCTION

This report provides insights into the experiences of maternity care for women of African and Caribbean heritage in the Lothian region and the challenges faced by NHS Lothian Maternity Services to provide person-centred and culturally sensitive care. The report makes recommendations to NHS Lothian and proposes an action plan to collaboratively improve maternity care and maternity outcomes for women of African and Caribbean heritage.

Background

Women of African and Caribbean heritage (WACH)⁴ aspire to positive and affirming pregnancies and births. Yet, they face challenges and disparities in accessing maternity care services in Scotland. The concerns about maternal and newborn outcomes and experiences- disproportionately poorer than those of women of any other ethnicity - are well documented and make for shocking reading. The reasons, whilst multifactorial, are founded upon deeply enduring historical imbalances in power rooted in systemic racism and structural exclusion. WACH have historically not been included in the knowledge generation to inform policymaking, health care delivery, design and pathways. They have not been involved in the critical strategic decisions that determine their well-being.

For this report, we are referring to the experiences of individuals assigned female at birth who may identify as women, non-binary or trans people. We define self-reported ethnicity as groups people belong to based on shared cultural, geographic ancestry, religion, language, diet and physical characteristics. This is distinct from race- an artificial way of ranking and categorising individuals based on physical appearances and their proximity to Eurocentric whiteness.

⁴ Individuals who have ancestral heritage to countries in Africa and the Caribbeans, regardless of their nationality and place of birth

We acknowledge that WACH are not a monolith or homogenous group. Whilst we do not speak for all WACH, in this report we aim to present the voices of those we have listened to.

We believe their stories will resonate and hold true for many across Scotland.

Pregnancy and Birth in Lothian

In 2022 there were 8725 births in Lothian. According to the Maternity electronic Records, 220 (2.7%) of these births were to women who self-reported ethnicity as either *‘Black British, Black Scottish, African, African Scottish, African British, Caribbean, Caribbean Scottish, Caribbean British or Other Black ethnicity’*.

Ethnicity reporting is incomplete and confusing in Lothian. In 12% of births ethnicity was either *‘Unknown or Not Given’*. In comparison to the Scottish Census ethnicity categories, the Lothian maternity records also include country of origin alongside ethnicity reporting.

In Edinburgh and the Lothians, the African population is mostly from the Western, Eastern, Central, and Southern parts of the continent. This includes countries such as Kenya, Nigeria, Gambia, Sudan, Somalia, Nigeria, Ghana, Uganda, Ethiopia, Malawi and Zimbabwe. We do not have information about the country of origin for the population of the Caribbeans. Majority of WACH who give birth in Lothian are cared for in the Pennywell, Sighthill, Tollcross and Leith antenatal locality areas.

The relatively small number of WACH women giving birth per year in NHS Lothian means that Maternity Services staff are unlikely to gain substantial experience in providing care to WACH.

At the time of writing this report, NHS Lothian was not routinely reviewing maternal and newborn outcomes and experiences by ethnicity.

However, in 2021 a qualitative study about published by *John et al*⁵ demonstrated evidence of poor experiences of maternity care in Lothian during the COVID-19 pandemic. Furthermore, as all UK maternity units are expected to submit data on adverse outcomes to national reports like MBRACE⁶ and UKOSS⁷ and these reports document disparities for minoritised women we believe it is likely that once disaggregated, Lothian data will demonstrate that WACH and their babies suffer a disproportionate number of adverse outcomes.

Pregnancy and Birth in Scotland

Relative to the general population minoritised ethnicity individuals form a larger proportion of people giving birth in Scotland. They are also more likely to live in economic deprivation.

In 2011 the Scottish census showed that 8% of the population identified as not White Scottish/British⁸. Recent Public Health Scotland Birth Reports indicate that of 44,557 maternities (a pregnancy ending in a live or stillbirth) in Scotland, minoritised ethnicity women accounted for 11% of maternities -5.4% were of Asian ethnicity and 2.2% of African, Caribbean or Black ethnicity⁹.

In Scotland majority of minoritised ethnicity pregnant women and people are cared for in NHS Lothian, NHS Greater Glasgow and Clyde and NHS Grampian.

⁵ Exploring ethnic minority women's experiences of maternity care during the SARS-CoV-2 pandemic: a qualitative study <https://bmjopen.bmj.com/content/11/9/e050666.long>

⁶ MBRACE produce annual reports into maternal and newborn deaths in Scotland. <https://www.npeu.ox.ac.uk/mbrrace-uk>

⁷ UK Obstetric Surveillance System is a national system of reporting and studying rare conditions in pregnancy <https://www.npeu.ox.ac.uk/ukoss>

⁸ Scottish Census 2011 <https://www.scotlandscensus.gov.uk/census-results/at-a-glance/ethnicity/>

⁹ Births in Scotland <https://publichealthscotland.scot/publications/births-in-scotland/births-in-scotland-year-ending-31-march-2023/>

NOTHING ABOUT US WITHOUT US

The Initiative

NAUWU is a community participatory initiative which aims to end disparities in maternal and newborn health outcomes and experiences for WACH in Lothian. We aim to do this through leveraging the partnership between KWISA as a community organisation and the NHS Lothian Maternity Voices Partnership (MVP).

Our efforts focus on championing advocacy, cultural safety and meaningful participation and engagement of WACH within maternity services. We hope to build on relationships and constructive exchanges between service users and providers to promote bidirectional learning and accountable co-production.

This initiative was funded by the Small Grant Scheme of NHS Lothian Charity.

The Partnership Model

At the heart of the initiative is the partnership between KWISA (African Women in Scotland Association) and NHS Lothian Maternity Voices Partnership (MVP). Before commencing this partnership, we collectively agreed on grounding and unifying principles to guide our process and reflection. Foundational to this is the African principle of Ubuntu, *"I am because we are"* - an acknowledgement of our interconnectedness, respect and collective responsibility in doing this work.



Each partner brings their expertise and connections: KWISA¹⁰ with the community of women of African and Caribbean heritage in Edinburgh & the Lothians and the MVP¹¹ with NHS Lothian Maternity Services and other 3rd Sector Organisations.

It should be noted that each partner has a broader remit:



KWISA(Women of African Descent in Scotland) was established for the development and empowerment of African women and their families so that they achieve their full potential in the community and society in Scotland, the UK and Africa

The MVP is a unique collaborative forum where the families who access maternity and neonatal services and the people who work for NHS Lothian get together to review these services. The charities and organisations that support families are also represented. Through open and constructive dialogue, the MVP aims to enhance the quality of care provided, advocate for women's and birthing people's choices and promote positive birthing experiences.



¹⁰ Learn more about KWISA www.kwisa.org.uk

¹¹ Learn more about MVP <https://services.nhsllothian.scot/maternity/maternity-voices-partnership-2/>

Women's Health • Research & Policy • Advocacy
Gender-based violence • Female Genital Cutting (FGM/C)

JOIN US



Our mission is to empower women of African descent in Scotland by addressing inequalities at the intersection of race, gender, health and socio-economic mobility.

We do this through

- Advocating and lobbying for inclusive policy change
- Delivering anti-racist community education and outreach
- Convening community expertise
- Conducting participatory research
- Building strategic partnerships



The Community Engagement Model

We facilitated a series of workshops and community engagement activities across Edinburgh and the Lothians to first understand the problem, and secondly initiate meaningful conversations bridging the gap between service providers and service users.



Each workshop set out to:

- Respectfully listen to the women of African and Caribbean heritage who attended.
- Sensitively hear their concerns.
- Collectively gather the rich cultural and traditional context.
- Systematically highlight the issues and map the gaps in the service.

We took care to create a safe environment for all who attended. Food, refreshments and a childcare play area were provided.

Participants were warned about listening to stories that could be potentially distressing. We sign posted spaces and NAUWU facilitators as opportunities to step away from emotionally challenging conversations.

The Community Workshops

The community workshops were held between November and December 2023.

In total 120 individuals cumulatively attended the five events. We offered a variety of formats: two meetings online and three in person. One of these events was held specifically for maternity healthcare providers in NHS Lothian.

The in-person events were hosted by several local community organisations to facilitate geographical access across the Lothians:

- KWISA in South Central Edinburgh

- Project Esperanza in Northwest Edinburgh
- KidzEco and African Women in West Lothian,

We deliberately chose to meet women in familiar community settings, ensuring they would feel safe and comfortable. We also provided activities for the children who came with their mothers.

Following introductory presentations, focus groups were facilitated by NAUWU volunteers. Participants were encouraged to respond to the following prompts:

1. *Your story is our story; what was your experience of pregnancy and birthing?*
2. *What my mother said and what I did- what were you told about what to do, not do in pregnancy? What did you do? How do you feel about this knowledge? Would you pass it down?*
3. *What matters to you?*
4. *What would you like to see from NAUWU?*

Responses were collected using, flip chart notes, audio recordings and “*What Matters to Me*” post-cards. All participants gave consent for their anonymised responses to be included in this report.

The Healthcare Provider Forum

We held an online separate forum for healthcare workers. Thirty-six participants registered in advance. On the day eleven people participated in the workshop. The workshop was recorded to allow dissemination with staff who could not attend on the day. This was shared with the NHS Lothian Women & Children’s Equality, Diversity and Inclusion Committee and staff mailing lists.

Attendees included a mix of midwives, doctors and NHS managers. The majority (80%) of participants worked in hospital and acute settings versus community (20%). All

attendees worked in Midlothian area. During this session, we provided the background to the initiative and shared some early feedback from the community engagement.

The participants were asked to respond to the following prompts.

1. What are the causes of ethnic minority maternal and newborn disparities
2. What are your initial reactions to what you've heard?
3. What is your experience of providing care to women of African and Caribbean heritage in your health board?
4. What do you think needs to be done around ethnic minority maternal and newborn care in your hospital (what support do you need)

Their responses were collected using an anonymous digital interactive whiteboard as well as verbal discussions during the forum.



VOICES FROM OUR COMMUNITY ENGAGEMENT

We listened to 120 people cumulatively across the five community events.

Many participants were women of African and Caribbean heritage who had either given birth in Lothian several years ago and/ or were the family and close friends of people who were recent service users. Few participants had recently given birth in Lothian. The event was also attended by representatives of third-sector organisations that support pregnant women and people who give birth in Lothian.

Your Story is Our Story

We explored participants experiences of pregnancy and birthing. Participants shared a mixture of positive and negative experiences.

Positive Experiences

Women shared positive stories with joy and pride. Memories of successful pregnancies after pregnancy loss; the first time seeing their baby after a long labour; enjoying loving prepared African or Caribbean food after being discharged from hospital; successfully breastfeeding after not managing with previous pregnancies.

Positive experiences were associated with the perception of feeling listened to and valued by their care providers. Positive experiences were noted when midwives provided *person-centred compassionate care* and supported women through difficult births. Specific examples were given when service users felt safer and more comfortable when the health care provider was also Black, African or Caribbean heritage.

Some reported expectations around positive pregnancies based on the positive stories and successes from their own family members or friends.

“My midwife really supported me. She really took her time with me. Listening around, now I see I was one of the lucky ones. I went to visit her with my baby and I send her photos”

“Thankfully I come from a family where people had successful births. My mother came and supported me so I thought that was just normal.”

“I was shocked to hear of negative experiences as mine was fine”

Some participants described more familiarity with doctor led care versus midwifery led care. They were surprised to never encounter a medical doctor throughout their pregnancy. However, some were positively surprised about efforts around shared decision making because they had previous experience of paternalistic health care systems.

Women who had positive experiences reported confidence in the expectation of future successful pregnancies, births and positive interactions with health care providers. Some were shocked to hear of negative experiences in maternity care.

Negative Experiences

Women described various negative experiences that could be classified into the following themes:

Loneliness

Women expressed feelings of loneliness, and raised issues around lack of support, particularly in the post-natal period. They spoke of the isolating consequence of feeling unheard, culturally misunderstood and inadequately supported throughout pregnancy,

childbirth and postpartum care, whilst sensing that other white women had received better care.

Some reported inadequate culturally nuanced communication and information during pregnancy and childbirth. They noted that cultural differences in healthcare expectations may have contributed to this.

I could have done with a companion to understand what was going on along every stage (of labour). My waters broke and I was left alone for 24 hrs.

My pain was not just physical. It was loneliness which added to my pain. If I had been at home, I would have been more supported.

Stereotypes

Women described examples of how negative stereotypes about Black people and culture negatively impacted the care they received. Common stereotypes included being perceived as stronger and more experienced with birthing, so needing less support. Health providers were reported to assume that WACH were less educated if they had a strong accent or limited language abilities. One woman described how her baby was swapped for the wrong Black baby despite the hospital system of tagging newborn babies.

“A midwife told me I thought you guys just go to the bush and drop the babies. We put in a complaint, but we were told all NHS staff are professional. They made it out that I had imagined it.”

“ There’s this misunderstanding that Black women are strong.

The first day after my c-section I was being bullied to go home. Why do I need to go home- because they need the bed.”

Poor Communication

Several women described examples of poor communication. These examples centred around having their concerns dismissed, belittled, not having things explained clearly or at all and delays in receiving care. The lack of information about what was happening during their pregnancy made the experience of a traumatic birth or pregnancy loss even harder.

One woman described the shock of learning for the first time that she had had a significant life-threatening blood loss whilst visiting her baby in the NICU (Neonatal Intensive Care Unit) when the neonatal nurses enquired about her wellbeing.

“My pain was dismissed for hours. I knew I was in retention but they left me like that for several hours. Now I have bladder issues. I’m a health care worker and even I couldn’t advocate for myself”

“If you're Black you have to buzz the buzzer 20 times before you're heard”

“ No one listened and I didn’t understand. It didn’t feel like they could be bothered to take their time with me.”

“ It’s almost like we have to demand otherwise we won’t be taken seriously. Next then they’ll say we are angry Black women.”

“Her story was one of not being listened to. She felt like she was in labour. But kept being told don’t come to the ward yet. Eventually, it got too much. She made her husband drive her to the hospital. At the reception, they said there’re no beds yet just wait. She had the baby standing at reception - in her corduroy pants



KWISA
Empowering
Supporting
Caring
Together

- ◆ KWISA is an African Women-led Organisation
- ◆ Established in response to the growing needs of Africans in Scotland
- ◆ KWISA's aim is the advancement of African Women and their families by providing spaces and opportunities to work together to address the issues that affect their lives.

WHO WE ARE



The themes of stereotypes and poor communication overlapped particularly around discussions of pain management. Some women perceived they experienced delays in recognising and responding to their pain. Few women gave examples of how they advocated around their pain using their ‘insider’ status as health workers or having a birthing partner who was male or White. Some of this was thought to be due to institutional racism, stereotypes, lack of recognition of different expressions of pain and some WACH being unable to comfortably express pain due to cultural expectations.

“ Language barriers can happen
yet you’re both speaking
English due to accents bias”

“ I felt that at some point in my journey, the
midwife did not understand me as much as I
would have liked her to. That was not her
fault. She was just lacking cultural
awareness”

Detection of Conditions in Darker Skin

Some participants recounted tales of misdiagnosis and late detection of poor wellbeing due to lack of awareness of how to diagnoses conditions in darker skin tones. Specifically, there were examples of delayed diagnoses and treatment of anaemia and jaundice.

***Peely Wally** doesn’t
apply to women with
darker skin**

*Peely Wally is a Scottish term used to describe someone who looks pale and sickly. Maternity health workers are not routinely trained on diagnosis of conditions on Black and Brown skin.

“I was severely anaemic but it wasn’t picked up until
late. I got an urgent transfusion. Then I lived in fear
about received blood transfusion because of the fear
of HIV”

“I knew my baby had jaundice, but I was told it was
just because he’s mixed race he has a tan. We had to
come back into hospital when he was 3 days old
because he was jaundiced”

Hypervigilance and Mistrust

Because of the above negative experiences, several women described developing a mistrust and hypervigilance towards health workers and hospitals. Several participants reflected that the unintended consequence of learning of disparities was fear and negativity amongst WACH. They advocated for more positive and successful stories to be shared widely.

“ It’s almost like you’re pregnant and you expect that something bad will happen because that was your previous experience or your neighbour’s experience”

“ My husband has to be around when I’m having a baby. He has to be a witness. I’m so scared of people making mistakes. But how many other women whose husbands don’t?”

“ There’s cultural differences where back home things seem so close knit, whilst here there’s a disconnect between the care provider and pregnant woman. How do we bridge this gap”



“Many women turn down routine care out of fear and distrust.”

What My Mother Said and What I Did

To understand ideas, behaviours and attitudes we encouraged participants to reflect on the different ways of knowing when it comes to pregnancy and childbirth.

Senior well-respected female members of families were frequently cited as a trusted reference point for pregnancy and birth including mothers, mother in-laws, aunts and older sisters.

Many also relied on their previous experience of maternity care to guide their expectations. This often was accompanied by disappointment if the experience of receiving maternity care in a different system was different from what was done in Scotland.

Women shared that specific cultural beliefs could be both positively affirming, but negatively isolating and confusing if they clashed with NHS advice.

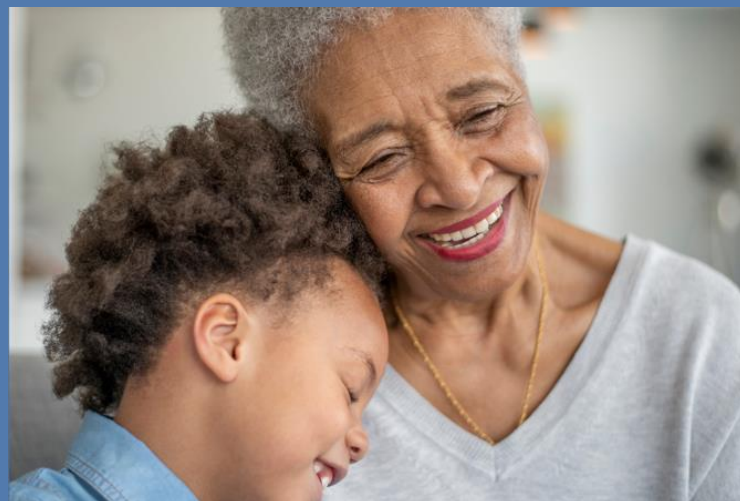
“I had my first baby in Kenya and then my second baby here(Edinburgh).

What I found difficult was the conflicting messages between what our mothers taught us at home and what we were being told to do here in NHS.”

“A lot of people are unlearning these old beliefs. Now It depends on your own values and what matters to you. Our mothers didn’t want us to be alone. They just wanted to protect us.”

“Grandmas are critical”

“So much to learn from traditional practices that rally around the mother. It’s the social connection that supports mothers.



Antenatally some women voiced superstitious beliefs around the importance of secrecy in the earlier stages of pregnancy to avoid pregnancy loss. In unpacking this myth, some acknowledged that this superstition was due to awareness around high rates of miscarriage.

Whilst women were able to control the narrative of their pregnancy with this, they acknowledged that this was isolating. For some this contributed towards poor mental health. Though people were discouraged from broadcasting their pregnancy they were still encouraged to engage with antenatal care services.

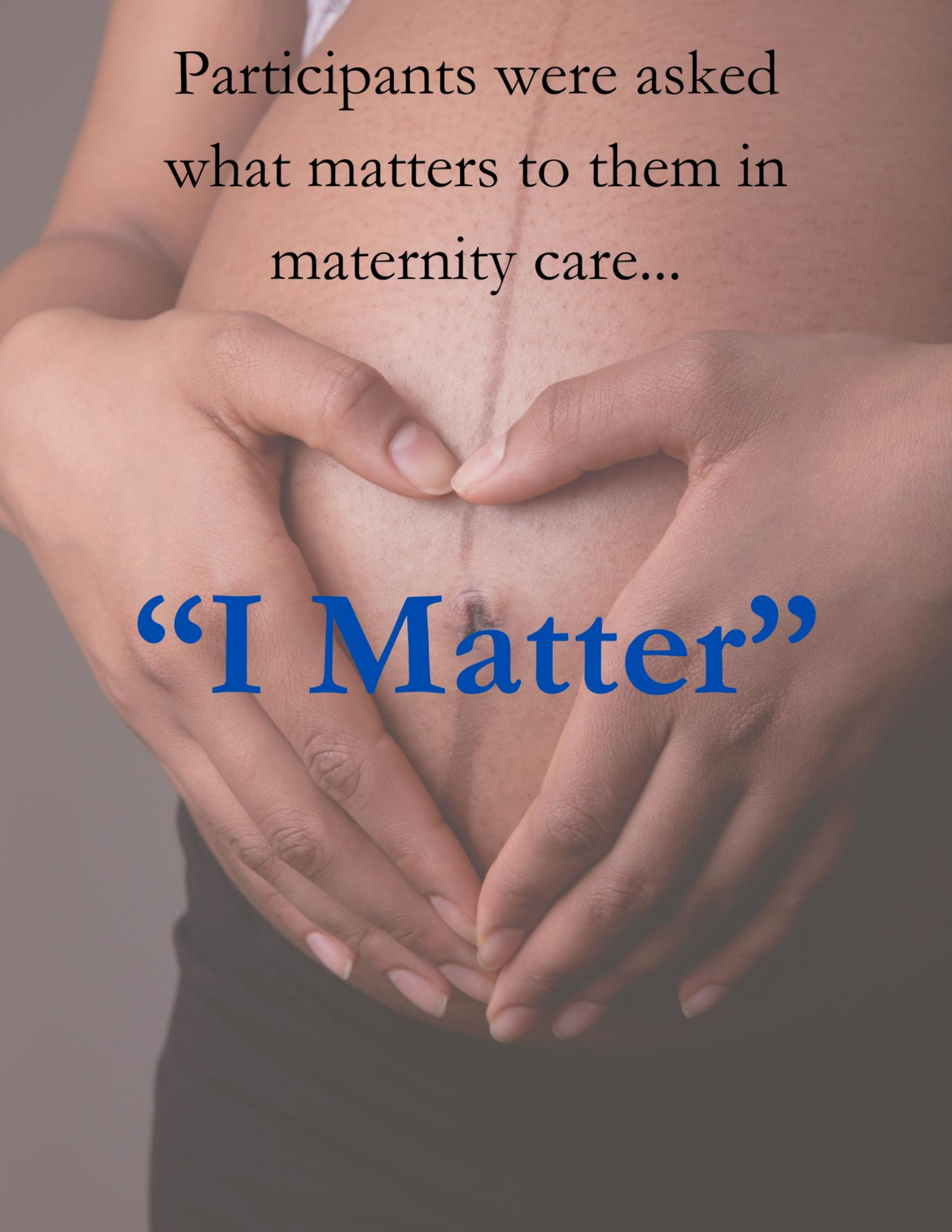
“ The secrecy means that
you’re suffering in silence.
You can’t ask for help
because nobody knows”

Contrasting cultural norms around pain

Pain came up frequently during community listening circles. Women acknowledged that cultural differences in expression of pain existed. One woman expressed confusion about the overt and loud expression of pain amongst White women in labour, noting that this would be frowned on in her culture. However, this attitude was not universally held by all WACH participants.

The aspiration to be ‘the strong Black woman’ was discouraged and felt to be harmful in getting your needs, fears and ideas addressed.

“ My mum told me African women don’t cry. For my first baby, I’m in pain and about to lose my mind and I’m there swallowing the pain. Until I came to Edinburgh and on the ward I heard women wailing and they were not even in labour. That was a whole culture shock. But years and years after that you have bottled trauma. I’ve had four babies now in this country and when I hear women crying in labour I think ‘Excuse me, be quiet. I’m trying to concentrate here”

A close-up photograph of a pregnant woman's bare midsection. Two hands, one from each side, are gently cupping and holding her belly. The skin is light-toned, and a vertical line of stretch marks is visible down the center of the abdomen. The lighting is soft and even.

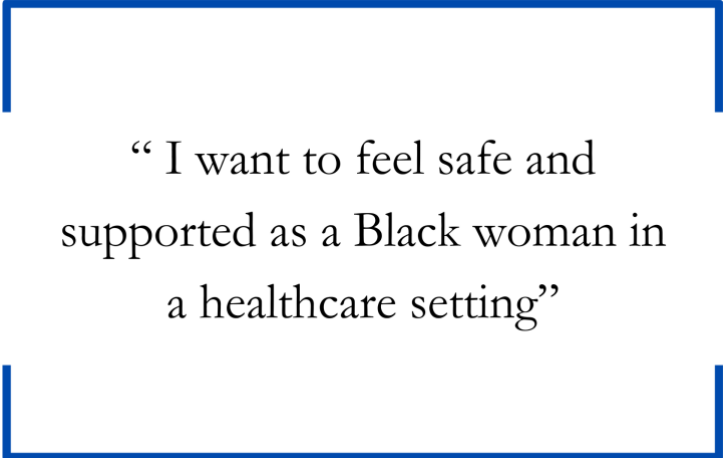
Participants were asked
what matters to them in
maternity care...

“I Matter”

What Matters to Me

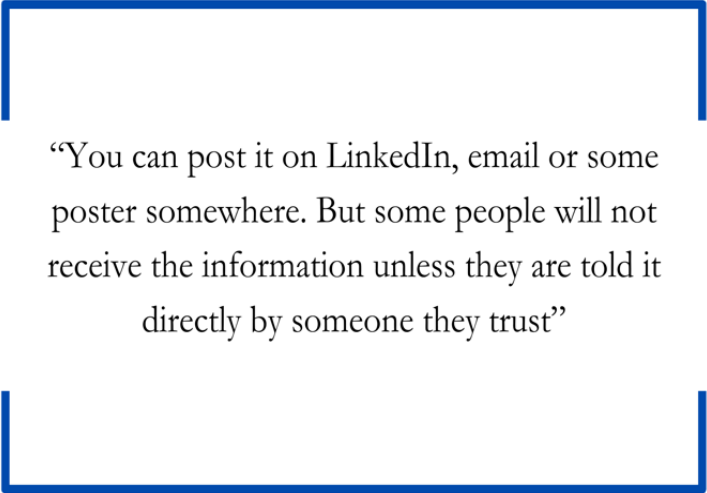
In the final listening circle women were asked to share what was important to them in pregnancy, birth, parenting and the future direction of the NAUWU initiative.

A key message we heard was around safety. Women wanted to feel safe as they navigated maternity spaces. Lack of perceived safety and ability to advocate for oneself caused fear, isolation and distrust of the system.



“ I want to feel safe and
supported as a Black woman in
a healthcare setting”

Safety was linked to trust. In order engage fully with maternity services women reported that they needed to feel like they could trust health workers and the hospital.



“You can post it on LinkedIn, email or some
poster somewhere. But some people will not
receive the information unless they are told it
directly by someone they trust”

Trust could be built by showing genuine curiosity and listening. Women wanted their providers to be curious about their specific needs and be open to diverse cultural ways of birthing as this was a significant part of how they navigated their pregnancies, births and parenting.

“ If you can bring out those words from our mouth, I know that’s not their job, but then if they can bring out those words from our mouth, many of us will be able to open up and really say what we need”

“ We grew up being told not to say too much, so I won’t be the first to tell you what I need when I come to the hospital. But if I see that you are asking and curious, then I will care to open up”

Community was perceived to be vital to having successful pregnancies and births. The adage ‘It takes a village’ resounded with many applicants. Community consisted of family and friends. Community acted as a support system and a source of knowledge around birthing. Some women expressed a desire for more culturally inclusive pregnancy support networks beyond routine antenatal classes.

“ I didn’t feel connected to the middle-class people in my antenatal class.

Participants repeated that receiving person centred individualised care was important. People wanted assurance that the health system would be inclusive and welcoming to allow all women to be authentic and comfortable in sharing their opinions and concerns. They wanted to be treated like human beings.

“Decolonise the mindset of staff so they perceive us as human”

“ I think most of them are nice. I believe if they know what I need then they will be able to act on that rather than what they think I need”

The women want to be heard by the hospital leadership and system. Women expressed feeling exhausted by engagement that was tokenistic with no accountability. Evidence of commitment to listening and valuing the lived expertise was proposed to build trust between the maternity system and communities of WACH. This could be demonstrated by being invited to participate in improving provider education, service delivery and policies in maternal and newborn health.

“The organisation needs to show that they are committed to really listening and changing. Then maybe people will be less defensive”

“ We would like an organisational invite to share our findings”

Positive stories were noted to be lacking in the narrative around minoritised ethnicity health. Women wanted to hear about more positive and successful stories of birthing for WACH. Positive stories were thought to help build confidence in the system and health workers.

“ **In the community, we want to hear more success stories!** Negative news travels more quickly than positive news. For me, I went into my first midwife appointment on the defensive. I heard you need to advocate for yourself. They will bully you. I kinda went into the first session ready to fight. But my experience was positive and I’ve been telling all my friends and family””

Women also wanted to be cared for by a more culturally diverse workforce which could address issues of cultural safety and mistrust. Finally, women expressed an urgent need for culturally sensitive spaces where WACH could connect with each other, especially after the birth of their babies (Pregnancy & Beyond Networks)

The participants made specific suggestions for improvement around the following themes:

1. *Cultural Nuanced Antenatal Education:* Provision of culturally nuanced education on prenatal health, navigating the maternity system, self- advocacy, pain- relief options in labour, management and prevention of diabetes, hypertension, sickle cell disease/trait, mental health and breast-feeding support
2. *Access to information:* Education should ideally be provided in multiple forums (online, in person, in community) and delivered by trusted community individuals.
3. *Community link workers who are WACH:* who would act as a liaison between women and the hospital and provide companionship like the AMMA Birth Companion model. These individuals should ideally be recruited from communities of WACH to ensure they had cultural sensibilities

4. Supporting development of peer networks for minoritised ethnicity women
5. *Increase the maternity workforce diversity*: Increasing the diversity of maternity and newborn workforce
6. *Diversifying NHS meals*: to include minoritised ethnicity options.
7. *Training of health care providers*: in anti-racism, implicit bias, cultural safety and detection of conditions in non-white skin.
8. *Accountability systems*: such as 360 feedback, transparent complaints and adverse review processes

“ We need more access to
information. Sometimes you
feel like you have to have access
to an insider to help you
navigate your pregnancy”

Specific to NAUWU, participants suggested:

1. Expand the model of engagement between health boards and community organisations outside Lothian
2. Collate and share stories from the perspective of advocates and health workers
3. Advocate for a community participatory hospital advisory board for WACH.

Healthcare Providers Forum

What is Your Initial Reaction to the Feedback from the community voices?

All participants acknowledged that they had some awareness of the existence of maternity health disparities for Black, Asian and minority ethnic women. This was predominantly due to prominence of MBRACE¹² reports.

Majority of participants believed that maternity care providers came to work with good intentions to provide the best care for all women regardless of their ethnicity and race.

“Nobody is 'taught' about White Scottish culture, but people seem to intrinsically understand. I think these differences are because staff are not curious and probably have implicit biases”

However, they acknowledged that widespread disparities existed in maternity and newborn care during and after pregnancy and birth in Scotland and likely in Lothian. They were not aware of any readily available data comparing outcomes by ethnicity

What Is Your Experience of Looking After WACH?

“(experience of working with Black women) is honestly quite limited. The majority of my patients are white, mainly British, which itself can cause barriers because you are not experiencing diversity of care”

There was a mixed response from participants regarding their experience for women from Black, African and Caribbean backgrounds.

Participants working in more acute areas reported having more experience, in comparison to those working in the

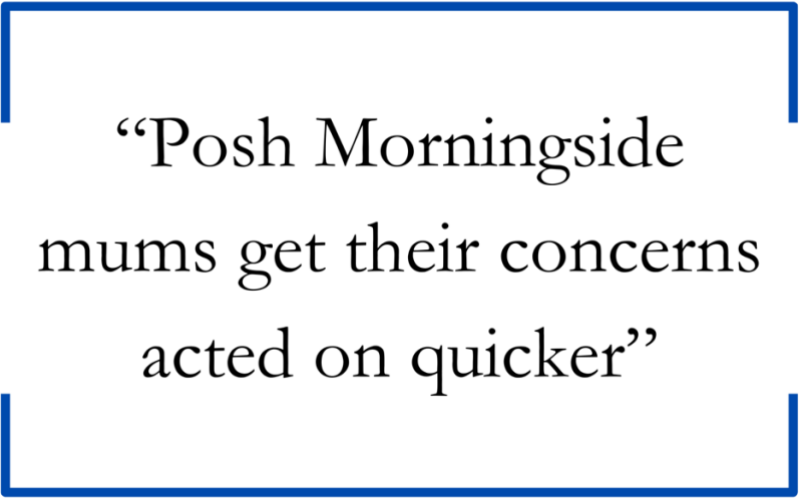
¹² MBRACE (Mothers and Babies: Reducing Risk through Audits and Confidential Enquiries across the UK) is a comprehensive annual report focused on improving maternal and perinatal outcomes in the UK. <https://www.npeu.ox.ac.uk/mbrace-uk/reports>

community setting. Due to the geographic boundaries, some staff work in areas with a larger White Scottish population and therefore have less experience.

What are the Causes of disparities for WACH?

Like the communities of WACH, NHS Lothian healthcare providers acknowledged that racism, discrimination and mistrust were drivers of disparities within the maternity care system.

Due to racism, xenophobia and classism, some participants reported that healthcare workers may be slower to respond to the needs of Black, African and Caribbean women.



“Posh Morningside
mums get their concerns
acted on quicker”

One respondent commented on how maternal and newborn disparities also existed for socially isolated white Scottish women living in economic deprivation.

Some participants gave examples of how intersectionality negatively impacted Black pregnant women with a non-Scottish accent who may be perceived to be from a lower socio-economic status. Immigrant women without asylum or refugee status may not have access to the same public services support that white Scottish women have, so are vulnerable to sudden change in their social circumstances.

“..all very important discussions.
So many of these points actually
apply to socially isolated Caucasian
women. So why do Black and
Asian women fair worse?”

“It’s not the same due to intersectionality
—white, socially isolated women have
different challenges to Black, migrant
women for example, look up “No
Recourse to Public Funds.
The same applies for non- English
speakers”

Participants reported gaps in staff knowledge around managing language barriers, racism, implicit bias, cultural safety, detection and diagnosis of conditions such as jaundice, anaemia, pain management and correct APGAR¹³ scoring in Black and Brown babies.

Lack of maternity care provider ethnicity diversity was felt to exacerbate knowledge gaps and discrimination as a driver of disparities.

Lack of time to support women with complex needs was frequently cited as an example of barrier to building trust and providing the best care. All participants reported that the NHS workforce crises and staff burnout also impacted the limited time staff had to spend with women with complex social factors.

MEHIS

A representative from the MEHIS group attended and shared the scope of their work. MEHIS is an NHS Lothian funded initiative which links people from ethnic minorities with a support worker. It can be accessed through self-referral or by referral through a healthcare worker. MEHIS helps people access different services within the NHS, 3rd sector charities and faith communities. MEHIS are members of the Lothian MVP. They currently have two male Black African and Caribbean link workers. Neither of whom specifically work with maternity but have engaged with Asian women experiencing challenges accessing diabetic care earlier in pregnancy.

¹³ The APGAR score is a quick check doctors and midwives use right after a baby is born to see how well the baby is doing and if they need extra help. It looks at five things: skin colour, heart rate, reflexes, muscle tone, and breathing, with a total score out of 10, where higher scores mean the baby is doing well

Birth Plan

A participant wanted a clear way for Black, African and Caribbean to express their individual needs, which led to a discussion regarding MVP involvement in the new updated birth plan. There are plans to make the birthing plans more individualised with an area for women to write about specific things that matter to them.

What Do You Think Needs to Be Done to Improve Things?

The health worker participants felt that positive change could happen if there was commitment from the health board, support for staff and additional resources provided. They gave specific examples of actions that could lead to an improvement in maternal health disparities:

1. Regularly reviewing data and outcomes for mothers and babies by ethnicity
2. Involving the Quality Improvement (QI) and Clinical Risk Team, to aid with data collection.
3. Prioritising research into specific conditions that impact Black women such as pre-eclampsia (raised blood pressure in pregnancy) and pregnancy loss.
4. Integrating cultural sensitivity and implicit bias training into regular staff study days.
5. Increasing staff awareness of the available resources and charities that serve Black, African and Caribbean women in Lothian.
6. Increasing diversity within the NHS workforce
7. Creating multi-disciplinary working groups involving communities of Black women to help bridge the gap, provide lived experience and rebuild mistrust

“If ethnic minority women tell us what they want what accountability mechanisms exist to make sure we hear them and act on their concerns?”





*If you want to go fast, go
alone. If you want to go
far, we must go together.*
- African Proverb



LOTHIAN
Maternity Voices
Partnership

OUR RECOMMENDATIONS

After a period of listening and reflecting on the themes from this extensive engagement, we have made recommendations specific to maternity service providers, maternity service users and the maternity service system.

PROVIDE ENHANCED PERINATAL CARE AND SPECIFIC SUPPORT FOR WOMEN OF AFRICAN & CARIBBEAN HERITAGE(WACH)

1. **Provide continuity of carer for WACH to address isolation, lack of support and poor communication**
 - Carers should be trained in providing culturally safe, anti-racist and unbiased care.
2. **Collaborate with third sector organisations specifically to implement community-driven solutions and lived experience to bridge the gap between women and healthcare services**
 - Develop a new role in community outreach workers/community champions to provide language support, education and advocacy
 - Aim for AMMA Birth Companionship model for example, such a model should be funded by the health board and Scottish Government
3. **Provide culturally specific antenatal education tailored to the needs of WACH using the following priority areas identified by the NAUWU community engagement exercise.**
 - Navigating the maternity system as a new service user
 - Pain management in labour (what are my options, benefits, risks)
 - Prevention and management of medical conditions in pregnancy- diabetes, hypertension, fibroids, endometriosis, sickle cell disease/trait, mental health conditions
 - NHS Complaints and Compliments Processes

- Self-advocacy, know your rights.

4. Request that Public Health Scotland co-design culturally specific pregnancy literacy resources to support antenatal education. These resources will inform women about available services and educate healthcare providers on diverse traditions and beliefs.

- Resources should be provided in different formats- written, audio visual, online, hard copies, etc.
- Resources should be provided in multiple languages and tailored to diverse literacy abilities.

5. Prioritise creation of community hubs in antenatal locality areas of the Lothians with the highest density of WACH- Pennywell, Tollcross, Sighthill, Leith and Craigmillar.

- Build trust amongst minoritised communities by situation NHS services, Local authority agencies and 3rd sector organisations under the same roof.
- Support the design of ‘Pregnancy and Beyond’ networks t

INCREASE CONSISTENCY OF MATERNITY STAFF KNOWLEDGE, AWARENESS AND COMPETENCE THROUGH SPECIFIC TRAINING

1. Commission and evaluate mandatory training for health workers focusing on cultural safety, implicit bias and antiracism

- Training should be led by WACH with lived expertise and experience
- Training should be delivered in multidisciplinary settings
- Training should be embedded within the existing health systems and educational curriculums to ensure sustainability
- Compliance with training should be monitored as part of Lothian’s assurance framework.

2. Promote bidirectional learning and trust building between service users and providers by supporting care providers

to participate in appropriate WACH community led activities.

3. In line with NHS Lothian Human Rights & Equality Strategy increase the diversity of maternity care providers over the next 5 years by intentionally recruiting and supporting career development of minoritised ethnicity individuals and tackling racism and discrimination within the health board. This will address multiple blind spots in the current NHS system.

IMPROVE SERVICE SYSTEMS TO ELIMINATE MINORITISED ETHNICITY DISPARITIES

1. Build trust and accountability with communities of WACH by demonstrating long term commitment to tackling disparities at the highest level of Health Board leadership. This will ensure that minoritised ethnicity issues are being valued and not tokenised or dismissed.

2. Proactively monitor and evaluate outcomes and experiences for WACH by embedding ethnicity disparity reviews into the Health Board data collection, clinical governance, assurance frameworks and improvement processes.
 - Improve the reporting of ethnicity data in NHS Lothian through staff education and quality improvement
 - Disaggregate and review adverse events, complaints and compliment by ethnicity
 - Embed S.M.A.R.T targets to eliminate ethnic minority disparities within the health board clinical governance and assurance frameworks including revision of relevant guidelines.
 - Based on baseline data, targets should be collaboratively agreed on with an advisory group of WACH

3. Enhanced collaboration with community organisations that serve and are led by WACH

- Invite an advisory group of WACH and relevant third sector organisations to set targets and co-produce Lothian specific strategy to improve outcomes for WACH.
- Commission and support funding into research investigating interventions to eliminate minoritised ethnicity disparities.
- Leverage the Health Board's relationships with academic institutions and Public Health Scotland to advocate for WACH to participate in the ideation, execution and dissemination of research investigating minoritised disparities.

4. Publish annual updates on progress on actions to reduce minority ethnicity disparities with community organisations.

5. Commission research into investigation co- produced interventions to tackle minoritised ethnicity disparities in perinatal health and wellbeing.

6. Share progress on the NHS Lothians Equality and Human Rights Strategy to tackle health inequalities, reduce discrimination and racism amongst staff and increase recruitment and career development of minoritised ethnicity staff

7. Celebrate the diversity of service users

- Support co-production of a multicultural collection of mothers' stories / motherhood across cultures/ lullabies/ night-time stories (a book for the Baby Boxes). Such a resource will be educational for care providers and promote inclusion by showcasing the diversity of our birthing population in Scotland.
- Diversify NHS in patient meal options by collaborating with established diverse caterers in Scotland.

CONCLUSION

In conclusion, this report offers a comprehensive analysis of the experiences of women of African and Caribbean heritage (WACH) within the maternity care system in Edinburgh and the Lothians. Whilst our findings may not represent the experience of all minoritised ethnicity women delivering in Lothian, our findings echo findings from published research¹⁴, AMMA Birth Outcomes and Experiences Report¹⁵ and FiveXMore Black Maternity Experiences Report¹⁶.

Our findings underscore the urgent need to address disparities and improve maternity healthcare for women of African and Caribbean heritage

Our recommendations provide a clear roadmap for building a more inclusive, culturally sensitive and equitable healthcare environment within women and children's services. Implementing these recommendations will require honest, concerted, collaborative efforts between communities of WACH, healthcare leaders, service providers, community organisations, academic institutions and policymakers. We acknowledge that positive change is mostly incremental but requires accountability to be sustained.

Whilst progress may seem daunting on the backdrop of financial crises within the NHS, we collectively believe that the cost of not acting is far greater.

Inequities by definition are *preventable, unjust and unfair*. We believe addressing inequalities for WACH will improve maternity and newborn care for all women and birthing people by improving safety, quality of care, resource allocation, service user and provider satisfaction and institutional reputation of Lothian Women & Children services.

We are ready to work with the Health Board to achieve our common goal.

¹⁴ John JR, Curry G, Cunningham-Burley S. Exploring ethnic minority women's experiences of maternity care during the SARS-CoV-2 pandemic: a qualitative study *BMJ* <https://bmjopen.bmj.com/content/11/9/e050666.long>

¹⁵ AMMA Birth Outcomes & Experiences Report (2024) <https://ammabirthcompanions.org/reports/birth-outcomes-experiences-report/>

¹⁶ FiveXMore Black Maternity Experiences Report (2022) <https://fivexmore.org/blackmereport>

RESOURCES

Where Can I Get Information on How to Have a Positive, Safe and Healthy Pregnancy?



NHS Lothian Resources

Your guide to your new world of being pregnant

<https://services.nhsllothian.scot/maternity/pregnancy/>

All you need to know about giving birth in Lothian

<https://services.nhsllothian.scot/maternity/all-about-birth/>

I've had my baby, what happens next?

<https://services.nhsllothian.scot/maternity/new-baby/>

Organisations that provide a wide range of support to parents and families

<https://services.nhsllothian.scot/maternity/mental-health-organisations-charities/>

Non-NHS Resources

TOMMY's

Specialist Midwife Helpline for Black and Black-mixed heritage Women and Birthing people

<https://www.tommys.org/pregnancy-information/about-tommys-pregnancy-information/video-call-service>

Royal College of Obstetricians & Gynecologists (RCOG)

Patient information leaflets

<https://www.rcog.org.uk/for-the-public/browse-our-patient-information/>

Held In Our Hearts

Support families who experience baby and pregnancy loss

<https://heldinourhearts.org.uk/>

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2.

LEARN

From our esteemed experts from videos to exclusive online events

3.

COMMUNITY

Build your village



SPOTLIGHT ON FIVEXMORE

Download the FiveXMore App, the first culturally tailored pregnancy and parenting app for Black women in the UK

FiveXMore is the UK's leading organization focused on Black maternal health. They offer free resources on hypnobirthing, self-advocacy and general pregnancy well-being resources

SCAN ME



RESOURCES

Organisations in Lothian that support and connect individuals and families of African and Caribbean Heritage

Multicultural Family Base

Tel: 01314677052

Offer an “Early Years” service that supports families during pregnancy and until your child is 3 years old

Edinburgh Caribbean Association

edincarib@gmail.com

Connect communities by promoting Caribbean cultural events and activities

Health In Mind

Tel: 0131 225 8508

Provide drop in mental health support for ethnic minority people in Edinburgh

Saheliya

info@saheliya.co.uk

Offer specialist mental health and well-being support for Black, minority ethnic, asylum seeker, refugee, and migrant women and girls (12+)



SPOTLIGHT ON PROJECT ESPERANZA

admin@projectesperanza.org.uk

Tel: 07538122152

Offer practical, emotional, and integration support that is racially, faith and culturally sensitive.

They specifically offer 1-to-1 advocacy and family support for pregnant women experiencing homelessness and vulnerable migration status concerning ‘No Recourse to Public Funds(NRPF)’.